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ABSTRACT

Although data indicate that Alzheimer's disease occurs among all racial and ethnic populations, the Alzheimer's disease support group system is used nationally primarily by white, middle-class caregivers. Developing a model ethnic-specific support group for Hispanics requires delineation of formal and informal health care networks in the ethnic community, training of indigenous group leaders, implementation of community compatible support groups, outreach to hidden caregivers, and evaluation of process and impact. A project developed by the Sun Coast Gerontology Center at the University of South Florida to provide direct service to Hispanic caregivers involved support group meetings held monthly in a Hispanic hospital and led by both gerontology professionals and indigenous leaders. The group was found to represent a fictive kinship network unit for participants who were primarily adult children of parents coping with Alzheimer's disease. The older generation Hispanics seldom attended the meetings. Although the fear of social stigma, the feelings about gossip being sinful, the tabu against revealing personal matters, the use of folk medicine, and the belief in the occult are problems specific to the Hispanic culture which may affect support group efforts, projects such as the Latin Alzheimer's Support Group can be therapeutic to Hispanic caregivers when developed and maintained in a culturally sensitive manner. (NRB)

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Creating Culturally Relevant Alzheimer's Support Groups for Racial and Ethnic Minorities

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Abstract

Although epidemilogic data indicate that Alzheimer's disease occurs among all racial and ethnic populations, family support group intervention as a helping modality is a middle-class, white phenomenon on a national basis. This pilot project shows that family support group intervention among Hispanics is a successful therapeutic modality when project implementors are sensitive to the culture of the Hispanic participant relative to implementation process, family dynamics, mental health beliefs, and participant age cohort effects.

Key Words: Hispanic, Alzheimer's disease, family support group, aging, ethnicity.

INTRODUCTION

The memory loss and intellectual decline of people afflicted with Alzheimer's disease and related disorders places a tremendous responsibility on their family members. The devastation imposed by Alzheimer's disease on patients and family caregivers cannot be adequately met by the formal health care system alone. Reliance on the informal health care system - that vast pool of primary caregivers, families, friends, volunteers, and paraprofessionals -is mandatory. While much information exists on informal health care beliefs, decision making, and health seeking behaviors (Parsons 1958; Friedson 1970; Fabrega 1974; Kleinman 1980) as well as aging, ethnicity and mechanisms of sociocultural insularity (Dowd and Bengston 1978; Holzberg 1982), there has heretofore been no attempt to combine these data into a unified statement for understanding ethnic groups in relationship to Alzheimer's disease and support group development as an effective vehicle of knowledge and assistance. This paper offers an advance look at the developmental model of a Hispanic Alzheimer's disease support group. The relentless increase of Alzheimer's disease and the lack of knowledge relating to minorities makes an advance report desirable for those contemplating such interventions.

The proliferation of Alzheimer's disease support groups in general is direct evidence of the ubiquitous nature and vigor of the informal health care sector in coping with dementing disorders. In response to the burden placed on family members to properly care for an Alzheimer's patient, self-help support groups have developed nationwide. However, the Alzheimer's disease support group system on a national basis is used primarily by a specific and limited population: white, middle-class caregivers. This user pattern constitutes an undesirable and unnecessary bottleneck to ethnic caregivers in need of help. This is particularly true in view of epidemiologic research which strongly indicates that dementing disorders are present in all racial and ethnic populations (Goldman 1984; Mortimer and Schuman 1981).

In a survey conducted by the author of twenty-three social/behavioral scientists is the United States professionally involved in aging and minority issues, not a single response was gathered regarding knowledge of or even the concept of extending Alzheimer's support group intervention into ethnic communities. Also, key people in the professional and volunteer aging networks were contacted in New York, San Francisco, Los Angeles, Memphis, San Antonio, Miami, and Tampa where significant ethnic populations live and where Alzheimer's disease support groups are in operation, but without any specific plan for incorporation or extension of services to minority caregivers and nearly zero participation in the existing groups by ethnic populations. It

is not surprising that the 1981 White House Conference on Aging specifically targeted blacks and Hispanics as ethnic groups whose informal mental health care systems were inadequately understood and in need of strengthening. However, an essential concept must be introduced early: to productively strengthen the coping capacities of ethnic caregivers, the intervention must not be hastily thrust into the existing helping network but must be incorporated into the health care system in such a fashion that it is an asset and not a competetive liability (Paul 1955; McDermott 1960; Polgar 1962; Foster and Anderson 1978; Kleinman 1980).

Ethnomedical data (Hughes 1968) such as functional characteristics of indigenous caregiving networks, caregiving understanding of the nature of Alzheimer's disease, and observations on how their beliefs impact on caregiving behavior must be known. Decisions on how to deliver primary care, when to seek non-professional or professional intervention, and how to allocate resources within the home in order to provide maximal support for all decisions made and re-made within the family setting in the socio-cultural context of the ethnic community.

In summary, this paper reports the experience of seeking to circumvent existing implicit or explicit disincentives to the use of family support groups among ethnic minorities by developing an Alzheimer's disease support group in the community of one of the nation's largest ethnic minorities: Hispanics. Developing the model ethnic-specific support group requires delineation of the

formal and informal health care networks in the ethnic communities, selection and training of indigenous support group leaders, implementation of community compatible support groups, outreach to "hidden" caregivers unresponsive to support group intervention, and evaluation of process and impact.

Alzheimer's Disease and Related Disorders:

The importance of Alzheimer's disease and other dementias is reflected in numerous publications (Rowe and Besdine 1982; Reisberg 1980; Mace and Rabins 1981). Many types of dementing diseases exist; Alzheimer's disease is the most prevalent leading to the frequent use of the term, but not ruling out other less common dementias. For purposes here, Eric Pfeiffer (1985) has most succinctly and eloquently described features of the disease.

> "Alzheimer's Disease is a devastating disorder. Its cause is not currently known and no truly effective treatment is yet available. It is a disease in which brain cells die prematurely and progressively, causing progressive memory decline and general intellectual deterioration.
>
> It is a highly variable disease whose course can run from 2 to 20 years after symptoms are first recognized. It is a disease which constitutes a major health problem in that it accounts for a large portion of persons admitted to nursing homes. Some 6.5% to 7% of all persons over age 65 suffer from it so that nearly 2 million people in the United States have Alzheimer's Disease. The number is expected to grow still further as more people attain advanced old age, particularly those age 75 and beyond.
>
> This is due to the fact that the prevalence of the disease increases with advancing age. Thus, at age 65, the incidence of the disease is only about 1%, while at 75 it has increased to 10-15%, and at age 80-85, it has increased to 20 or even 25%,

resulting in the average figure of 6.5-7% for all those persons age 65 and over. Yet it is important to emphasize that Alzheimer's Disease is not simply a manifestation of old age. Even at age 80-85, 75% of older persons are not afflicted by this disease.

Depending on the personality of the individual affected by the disease, the symptoms may include depression, irritability, social withdrawal, decreased work performance, and occasionally isolated acts of inappropriate behavior. Sometimes a spouse notices difficulty in the marital relationship and may seek marital counseling. At other times work performance becomes so poor that the individual may be at risk of getting fired or retired prematurely. When any of these symptoms occur in persons in their 50s, 60s and in their 70s, it is important to be alert to the possibility of Alzheimer's Disease.

Alzheimer's Disease has an increasingly harsh impact on the affected patient. Initially only some mild personality changes occur. As the disease progresses, frank memory deficit occurs and the ability to perform decision making functions decreases. As the disease further progresses, the person's capacity for managing his own affairs and his own household, as well as caring for his own person, in terms of his activities of daily living, also becomes impaired. Still later, the ability to speak and to find words and to respond to the communications of other also decreases and finally disappears altogether.

In the end, some of the automatic bodily functions, like swallowing and toileting functions, also disappear and the person becomes entirely dependent on someone else. This is the direct impact of the disease. However, many patients in addition develop depression, anxiety, agitation, delusions and paranoid ideas in response to their illness, which further complicate their care and increase their own suffering and that of the caregivers around them.

Alzheimer's Disease really produces two victims, the patient and the primary caregiver. Caregivers must make enormous adjustments to the occurrence of Alzheimer's Disease. They must gradually

assume increasing and later total responsibility, not only for their own functioning but for that of their affected spouse as well."

Aging and Ethnicity: The ethnic experience of aging has often been discussed from two primary viewpoints: 1) Double or multiple jeopardy, and 2) aging as leveler. According to Markides (1983), the double jeopardy hypothesis was derived from the National Urban League in the 1960's and the National Council on Aging in the early 1970's. The "age as leveler" perspective considers ethnicity independent from a more important shared disadvantage, that of minority status. The explanatory value of each perspective is a matter of debate. Along the dimensions of income, health, family relations, and psychological well-being, Markides (1983) shows a complex set of interactions which do not offer strong empirical support for either perspective. However, this does not mean that these two phenomena are not in effect.

More recently, Holzberg (1982) suggests that the concept of ethnicity has been inappropriately used to refer only to social status or stratification. Holzberg points out that what has been missing is the cultural factor of ethnicity. In any case, the facts of ethnicity, aging, and dementia as sociocultural phenomena are compelling reasons for understanding how a significant portion of the American public experiences old age, particularly when compromised by chronic, organic brain disease.

The need for outreach in mental health services to elderly Hispanics was recognized formally at the 1981 White House Conference on Aging. For Hispanics, "...research and programs should be carried out concerning informal support systems of older Hispanics. Programs to enhance these non-institutional mental...supports should be initiated (Licayo 1981)."

Also, Becerra, Karno, and Escobar (1982) have completely reversed the popular view of the 1950's that Hispanics were less prone to psychiatric problems by compiling a volume which focuses on Hispanics and mental health issues relating to sociocultural influence, major syndromes, and service delivery strategies all specifically tailored to various Hispanic populations.

Stereotypes of ethnic elderly populations have been noted for virtually all major ethnic groups in the U.S. (New, Henderson, and Padgett 1985). Specific to Hispanics, David Maldonado (1985) has indicated that policies must be based on an accurate appraisal of real life circumstances for the various Hispanic populations. Also, Maldonado notes that Hispanic age cohorts respond differently to service delivery options. For example, the older Hispanic population who developed coping strategies during pre-civil rights decades will have a greater reliance on self-sufficiency leading to underuse or misuse of the service delivery system. On the other hand, the adult children of these elderly Hispanic people were socialized in this society during or after civil rights reform and have a more active

response to existing service delivery systems. The age cohort effect has a significant influence on family support group intervention for Alzheimer's disease patients.

Social Networks and Health Care: An expanse of literature exists regarding the topic of social networks. Social networks include contacts with relatives, friends, neighbors, etc., through which individuals maintain a social identity and receive emotional support, material aid, services and information, and develop new social contacts (Walker, McBride and Vachon 1977). However, of importance here is the function of the social network as a helping technology in terms of health and disease, specifically related to dementing disorders among elderly people.

While some have suggested features of social networks as influential in the etiology of disease (Cassel 1976; Cobb 1976), of interest here is the social network as an indigenous system related to health seeking behavior characterized by use of lay consultation, referral, and self-treatment (McKinley 1981).

Social networks have been observed in place and action among older people worldwide. The depth of complexity of these helping networks is astounding. What can be documented is that such networks do exist and have unique patterns depending on the nature of the health problem and the community in which the network exists. Goodman (1984) has shown a variety of helping styles within a retirement high rise complex. Morgan, Patrick, and Carlton (1984) have demonstrated the complex network of social ties among physically challenged people who initially

appeared to be isolated and having little capacity to develop helping networks. Furstenberg and Davis (1984) have shown that lay consultation among old people is a vital element in the lives of those who share diseases with a sizeable proportion of their age mates. Studies show that elderly people in inter-city SRO hotels are capable of having working networks (Sokolovsky and Cohen 1980). Even in institutional settings, patients who at first glance appear to be depleted of the resources to develop and maintain a social network, have quietly but pervasively demonstrated surprising resourcefulness in developing patterns of support involving other patients and staff (Henderson 1981; 1985).

In other cases, specialized networks among elderly people have been created outside age segregated communities then incorporated into the existing system (Pynoos, Hade-Kaplan, and Fleisher 1984; Henderson and Cairl 1983). In both of these studies, the informal network pathways were already established and operating and available for added information and enhancement.

In summary, elderly people fluidly interact with one another in their communities on matters related to health and disease. Old people in residential communities, old people in high rise complexes, and old people in institutions are all shown to be active participants in a social network of health seeking behavior.

Support Groups: The acute illness and physician-patient relational model of health care has failed to meet the needs of the elderly people experiencing chronic ill health specifically related to dementing disorders. This applies to other diseases as well and has resulted in the development of "self-help clubs" (Hill 1979, personal communications) as an adaptive response to chronic illness and disability (Gussow and Tracey 1976). According to Caplan and Killilea (1976), support groups form because there is feeling that the traditional system fails to properly take them into account and the self-help group becomes an alternative to the formalized service delivery system. Gussow and Tracey (1973) suggest there are two primary types of self-help groups. Type I is characterized by direct services to family members and patients. These groups can be divided into four subgroups: a) rehabilitative, b) behavior change groups, c) primary care groups in which people deal with chronic disease for which there is no recovery and d) prevention and case finding groups. Type II support groups are classed as indirect service providers in that they emphasize macro political and economic activities. It is Gussow and Tracey's Type I subtype c and d groups that have been used in this project to provide direct services to ethnic caregivers in need. In relation to Type I subtype c and d groups, Middleton (1984) finds that members of specific self-help groups have a basic common denominator - they share a central problem. It is a problem that brings them together as a group and it is that problem upon which the group

is focused." Furthermore, Middleton (1984) points out that self-help groups often include or center about the patient with the initiating problem whereas family support groups focus on family members or the primary caregivers of the patients. It is the family support group approach that has been used in this project.

LATIN ALZHEIMER'S DISEASE SUPPORT GROUP

History: The Suncoast Gerontology Center for Health and Long-Term Care is one of eleven research stations on aging funded by the Administration on Aging. In 1980, the Suncoast Gerontology Center was involved in a human subject drug experiment with a compound intended to improve the symptoms of Alzheimer's disease. Subjects were brought to the experimental site by family members who waited in an adjacent room and were often found to be exchanging information on caregiving strategies and empathizing with one another. From that observation, the Center's psychiatric social worker, Lillian Middleton, developed an Alzheimer's disease support group affiliated with the Suncoast Gerontology Center. The Suncoast Group was a professionally led group. Membership in the group was open to all and was widely known in the Tampa Bay area via several media reports. The group acquired new members rapidly and meetings were often attended by 60 to 100 people.

In September, 1983, I turned my attention to the functions of Alzheimer's disease support groups. I observed that the entire population attending the support group was white and

middle-class. A quick check of the epidemiologic data showed that Alzheimer's disease afflicts all populations with equal risk. This was all the more noteworthy in that the Tampa Bay area has a significant Hispanic population. For example, the Hillsborough county black population 65+ is 7.9% of the total population while the Hispanic 65+ population is 13% (Longino 1983). Therefore, it was decided that a prototypical project would be initiated to determine if there were significant cases of Alzheimer's disease among Hispanic people in the community and secondly, to initiate support groups which were culturally relevant for those populations.

A targeted ethnographic survey of the Hispanic community was conducted focusing on health care beliefs and behaviors specifically related to aging and mental health. The ethnographic survey methodology was selected precisely for its capacity to reveal detailed empirical, verifiable, and reliable data upon which reasonable action could be based. The survey produced results regarding the formal and informal health care sectors emphasizing the health seeking behavior of caregivers responding to dementing disorders in their households and families.

In order to assist us with the pilot project and the ethnographic study a member of the Latin community was sought as a key informant and possibly an indigenous support leader.

The first search was through Aging Services in Hillsborough County. Contacts in this agency led us to a Senior Day Care Center located in the historic Hispanic district of Tampa called Ybor City. One of the Day Care Center aides was a bilingual Latin who had family experience with dementia. This female in her forties was contacted regarding her interest in serving as a support group leader. Her supervisor would allow her to have compensation time for the hours that she would use in conducting a support group. These hours were estimated at 4 hours to 5 hours per month. Having gotten supervisory permission and a willingness to work on the part of the indigenous support group leader, the issue of training arose. The decision was made to train the leader based on didactic training at conferences conducted by the Suncoast Gerontology Center on dementing disorders and to conduct a series of three small group discussions with her. In addition to this, it was decided that the support group meetings would take place and be jointly led by the psychiatric social worker who was experienced with groups and to allow the indigenous support group leader to engage in role model training so that she could on a gradual basis begin to exert more influence in group dynamics.

The meetings were scheduled to be held monthly and led by two professionals from the Suncoast Gerontology Center as well as the indigenous support group leader. The location suggested by the indigenous group leader is a Hispanic hospital in Tampa, Centro Espanol Hospital. Announcements were run in Spanish

language newspapers and on Spanish speaking radio stations in the community. Word-of-mouth communications also led to participation through contacts that the leader had through her day care center activities. Lillian Middleton also identified potential attendees via her contacts in the community.

These activities led to the initiation of a support group meeting that was considered attractive to Latins due to 1) the participation of a Hispanic support group leader, 2) the use of project implementors as "outside" consultants, 3) the use of Centro Espanol Hospital, a culturally relevant symbol in their health care domain. Thirteen Latin Alzheimer's support group meetings have taken place. Thirty Latin contacts have been made thus far, predominantly by using the group leader's knowledge of her community and word of mouth. The epidemiology of Alzheimer's disease predicts that we will contact many more Latin people coping with the disease as the project continues.

Ethnic Specific Features: One of the assumptions tested by this pilot project was the appropriateness and utility of support group intervention which works well among white middle-class Americans as a proper intervention among Hispanic populations. Some investigators suggest that group psychotherapy which is akin to family support group intervention, is prone to failure among Hispanics due to members' concerns about privacy (del Valle and Usher 1982). However, del Valle and Usher note that with proper empathy from group leaders such concerns can be overcome. Other specialists agree that there are positive benefits of Hispanic

group meetings. For example, Acosta (1982) reports that while group psychotherapy among Hispanic people is not currently common it "...can be a powerful modality in treating the Spanish speaking Hispanic patients." Becerra, Karno, and Escobar (1982) state even more positively that.

> One type of treatment strategy that has proven very useful with the Spanish speaking Hispanic has been group psychotherapy. The group acts as a support system that facilitates the disclosure of private experiences that many Hispanics find difficult to communicate outside the family or community setting. The all Hispanic group serves to promote greater identity and cohesion among the group members. The similarity in culture and lifestyle provide an environment that is conducive to openness, understanding and change.

The experience of this pilot project is consistent with the predictions that the support group will represent a fictive kinship network unit in itself. Thus, the support group serves as a form of the extended family with a problem focus coping with Alzheimer's disease. According to Escobar and Randolph (1982) the extended kinship network is a primary social resource among Hispanics and there is strong reliance on the "concepto de la famililia" as a key element in Hispanic culture.

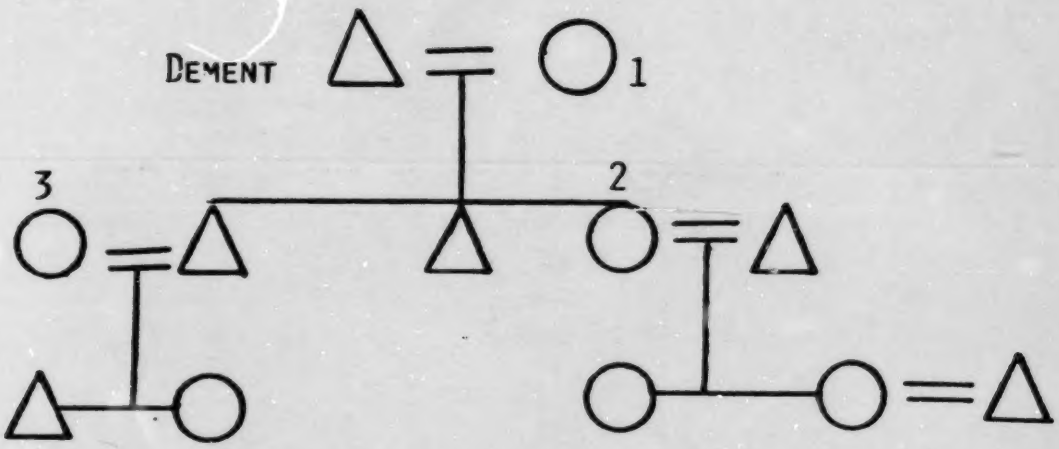
David Maldonado (1985) suggests that Hispanic populations variably respond to available helping services such as Alzheimer's family support groups by age cohorts. This age cohort effect has been very clearly observed in the Latin Alzheimer's Support Group. The most active members are adult daughters and sons of parents who are coping with Alzheimer's disease. The older generation Hispanics thus far seldom attend the group except when specifically brought by

their daughters or sons. Furthermore, when knowledge of additional community resources are made known to the parent generation, arrangements for such resources are negotiated through the adult daughters or sons in the group.

The prominence of the Latin kinship and family dynamic structure is very clear in issues related to burden bearing and responsibility. The foremost of these is the sex biased pattern of familial transmission of responsibility for care of the demented patient (see Figure 1). Members commonly report that there is the practice of women being looked to for providing care for the demented person whether it be the women's spouse or whether it be a parent or a parent-in-law. When the family has males and females "available" for providing the major burden bearing responsibility, it is the female who is expected to provide that type of care. One informant reported that during the life of the patient (her father), her mother and she would be expected to provide the bed and body care (cf. Gubrium 1975) for the patient but that when death occurred, her brothers would take charge of the father because now it entered a business dimension, namely the funeral as a cost item and public display.

If the family does not have a consanguineal female to provide bed and body care for the patient, these duties will be assigned to an affine, notably a nearby daughter-in-law. This provides a source for a variety of intra-familial irritations. For example, many Hispanic parents are concerned that their adult children may disengage from family responsibilities with the parents. In fact, a daughter-in-law is often the target of great hostility because she

Hispanic Family Favored Burden Bearers



1 = Primary Caregiver

2 = Secondary Caregiver

3 = Tertiary Caregiver

FIGURE 1

has removed the son from the immediate purview of the family arena (del Valle and Usher 1982). Nonetheless, the daughter-in-law may be pressed into service to her in-laws.

Alzheimer's disease carries with it symptoms which the general public would interpret as characteristic of someone who is "crazy". The stigma attached to mental disorders is well known within this culture and many others. Escobar and Randolph (1982) report that, "For many Hispanics, mental illness is still seen as a dreaded affliction akin to 'mal de Sangre' or 'bad blood'." The issue of a family member being "crazy" is a common one in the Latin Alzheimer's Support Group meetings. There is often a personal crusade launched to be sure that friends and family understand that Alzheimer's disease is an organic disease and therefore not under the control of the individual, thus relieving the patient and family of social stigma liability.

There are also two related ethics within the Latin community which can interrupt the benefit of a support group as an intervention mode. These are 1) the sin of gossip and 2) the tabu of revealing personal matters in public arenas (del Valle and Usher 1982). In group meetings when the adult children have been able to bring their parent who is providing most of the day-to-day care for the demented patient, these older parents have been nearly silent during the group meetings leaving the younger generation to proceed along behavioral pathways more in line with American middle-class whites. The adult daughter or son is often explicit in private interviews about their parent's cultural values of preserving a proper image of the family

in public settings. It is as if the adult offspring are the cultural brokers of information and services from the support group to their aged parents.

Folk medical practices are not discussed in the group setting. In individual interviews in the homes, informants likewise deny that they use any specific folk remedies. In Ybor City, however, there are botanicas which sell a variety of folk medicines including herbal remedies as well as spiritualist and occult paraphernalia. Inquiries at these shops reveal the presence of materials usable for old people who are suffering a memory decline and are reported as frequently sold. Spiritualists or occult beliefs are not revealed in the Latin Alzheimer's Support Group settings, although del Valle and Usher (1982) report that such topics eventually emerged in their Latin psychotherapeutic groups.

DISCUSSION

The 13 months of the Latin Alzheimer's Support Group pilot project has shown that there is a significant Hispanic population in need of family support group services to assist in the coping process necessitated by the presence of Alzheimer's disease in the family. At first there was some skepticism that there was no service population for such a support group. However, with minimal effort the project revealed a few dozen Latin people impacted by Alzheimer's disease who were not users of the well publicized Alzheimer's disease support group operated for three years previous at the Suncoast Gerontology Center. The experience thus far has indicated to us that this is a "tip of the iceberg" phenomenon.

The purpose of a pilot project is to learn through experience as part of an ongoing process. Items that the project has taught us are worth emphasis. First, there is a definite benefit to the family member participating in an ethnic specific Alzheimer's disease support group. As Acosta (1992) has termed it the group becomes a "mini-community." The issue of cultural relevance is critical particularly if the initiators of such projects are non-Hispanics. The formation of an alliance with an indigenous member of the Hispanic community who is bilingual and has some knowledge of the aging services network is very critical. Also, the use of ethnic specific media for announcing the group to the community proved to be a very useful vehicle for ethnic specific communication.

Second, the experience of this project shows that those attracted to attendance at the Latin Alzheimer's Support Group were middle-class, bilingual Latins. It appears that support groups are most attractive to middle-class, middle-level educated people. Moreover, those attending the group are very likely the adult daughters or sons of the parent who is coping with a spouse who is a victim of Alzheimer's disease. It has been helpful to perceive the adult children as the brokers of information and cultural styles of receiving health care assistance. The bulk of the group members bridge the cultural gap associated with the project initiators from the University Medical Center to their parents whose interactional patterns with "authorities" cause them to appear quiet and passive relative to their adult children.

Third, there is the problem of the "hidden caregiver". Despite even highly sophisticated and ethnically sensitive approaches for involving caregivers and developing support groups, some caregivers remain hidden and uninvolved, despite, or even because of great distress and perceived cultural incongruity with the majority society. To these persons, trained indigenous support group leaders can be especially helpful.

Detection of hidden caregivers is inherently difficult. However, the following strategy is suggested as at least one device to identify Hispanic caregivers in great need. A "Hidden Caregiver Search Protocol" has been developed and consists of a communication and follow-up approach. Members of the helping professions should be alerted to the presence of the ethnic specific dementia support group by the receipt of a flyer announcement with ethnic specific line drawings of concerned elderly persons or a couple prominently centered and surrounded by detailed information. These flyers should be sent to health care providers and other helping professions as well as to members of the aging network. Also, community organizations should be alerted to the support groups with the same flyers. Such organizations include day care centers, social clubs, hotline crisis intervention programs, and community business groups. Additionally, the support group should be made known through the local Hispanic media.

Members of the above organizations should be asked to request their associates to assist them in scanning their local kin and friend networks for elderly people with memory or intellectual

dysfunction. As each lead is pursued the greater the likelihood of success in bringing undetected cases to the assistance of support group intervention (see Figure 2).

The second phase of the search protocol is the "Case Verification Protocol". The Center's pilot project has shown that it is necessary to screen potential participants in the support groups for those who would be inappropriate or disturbing to the productiveness of the group. Therefore, a protocol for screening has been developed (see Figure 3). Having once determined appropriateness, the caregiver is invited to participate in the project either through support group attendance, receipt of information via home visits by the indigenous leaders, or assistance in the use of educational materials.

In summary, these guidelines are usable in the development of ethnic specific Alzheimer's disease support groups in many Hispanic communities. The concept of ethnic specific dementia support groups is one which requires continued problem-focused research. Research activities should center about further knowledge of the epidemiology of Alzheimer's disease in ethnic populations, the variable impact of support group intervention by socio-economic class and age cohort. Furthermore, the potential negative effects of support group formation must be explored. For example, David Maldonado (1985, personal communication) considers support groups which rely totally on community resources, a non-service strategy. Also, involvement in a support group can generate expectations of mutual reciprocity among group members who may be already operating at their physical and

financial resource limit and, therefore, perceive the interactions with group members as an additional strain. Nonetheless, the weight of the literature on Hispanic group psychotherapy and the experience of the Latin Alzheimer's Support Group pilot project show that such interventions successfully play a therapeutic role in promoting the health and well-being of Hispanic caregivers to Alzheimer's disease patients when developed and maintained in a culturally sensitive manner.

"Hidden Caregiver": Search Protocol

1. Alert members of the helping professions to the ethnic specific dementia support groups via 8"x10" "flyer" announcements with ethnic specific line drawings of concerned elderly person or couple prominently centered and surrounded by detailed information.

   - Physicians
   - Community Health Clinics
   - Police
   - Ministerial Alliance
   - Area Agencies on Aging
   - Hospitals
   - Community Mental Health Centers
   - Aging and Adult Services

2. Alert community organizations with same flyers.

   - Day Care Centers
   - Social Clubs
   - "Hot line" Crisis Intervention
   - Business Groups

3. Alert ethnic community media.

   - La Gaceta (Hispanic Newspaper)
   - WAMA (Hispanic Radio)

FIGURE 2

"Hidden Caregiver": Case Verification Protocol

1. Call or visit possible cases.

2. Rule out:

   a. Chronic mental illness
   b. Alcoholism
   c. Simple incorrect referral for other disease/disorder

3. Ask if a diagnosis by a physician has been made.

4. If not, ask if symptoms:

   a. appeared slowly over a long period of time
   b. if recent memory is a problem
   c. if distant memory is still intact

5. If answers to question #4 are positive, invite participation in:

   a. support group
   b. home visits
   c. written information

6. Initiate Network Development

FIGURE 3

REFERENCES CITED

Acosta, F.X. 1982 Group Psychotherapy with Spanish-speaking Patients. In Mental Health and Hispanic Americans. R. Becerra, M. Karno, and J. Escobar, eds. Pp. 183-1988; New York: Grune & Stratton.

Becerra, R., M. Karno, and J.I. Escobar 1982 Mental Health and Hispanic Americans: Clinical Perspectives. New York: Gene & Stratton.

Caplan, G. and M. Killilea 1976 Support Systems and Mutual Help. San Francisco: Jossey-Bass.

Cassel, John 1976 The Contribution of the Social Environment to Host Resistance - The Fourth Wade Hampton Frost Lecture. American Journal of Epidemiology #2, 102:107-123.

Cobb, S. 1976 Social Support as a Moderator of Life Stress. Psychosomatic Medicine 38:300-314.

del Valle, A. G. and M. Usher 1982 Group Therapy with Aged Latino Women: A Pilot Project and Study. Clinical Gerontologist 1:51-58.

Dowd, J.J. and V.L. Bengston 1978 Aging in Minority Populations: An Examination of the Double Jeopardy Hypothesis. Journal of Gerontology 33:427-436.

Escobar, J. and E. Randolph 1982 The Hispanic and Social Networks. In Mental Health and Hispanic Americans. R. Becerra, M. Karno and J. Escobar, eds. P411-60. New York: Grune & Stratton.

Fabrega, H. 1974 Disease and Social Behavior. Cambridge, Massachusetts: MIT Press.

Foster, George M. and Barbara G. Anderson 1978 Medical Anthropology. John Wiley and Sons, Inc.

Friedson, Eliot 1970 Profession of Medicine: A Study of the Sociology of Applied Knowledge. New York: Dodd, Mead & Company.

Furstenberg, A. and L. Davis 1984 Lay Consultation of Older People. Social Science and Medicine 18:827-837.

Goldman, R. 1984 The Epidemiology and Demography of Dementia. Psychiatric Annals 14:169-174.

Goodman, C. 1984 Natural Helping Among Older Adults. The Gerontologist 24:138-143.

Gubrium, Jaber F. 1975 Living and dying at Murray Manor. New York: St. Martin's.

Gussow, Z. and G. S. Tracy 1973 Interim Status Report: Voluntary Self-Help health Organizations, A Study in Human Support Systems. Louisiana State University, Baton Rouge.

Henderson, J.N. 1981 Nursing Home Housekeepers: Indigenous Agents of Psychosocial Support. Human Organization 40:300-305.

Henderson, J.N. 1985 Long-Term Care Patienthood: Resourcefulness in a Presumed Resource Meager Environment. In review.

Henderson, J. N. and R. Cairl 1983 Health Watch: A Mechanism for Diffusion of Geriatric Health Information in Age Segregated Communities. Southern Gerontological Society meetings. Atlanta, Georgia.

Hill, R. F. 1979 Personal Communication.

Holzberg, C. 1982 Ethnicity and Aging: Anthropological Perspectives on More than Just the Minority Elderly. The Gerontologist 22:249-257.

Hughes, C. 1968 Ethnomedicine. In International Encyclopedia of the Social Sciences. 10:87-93. New York: Free Press/MacMillan.

Kleinman, Arthur 1980 Patients and Healers in the Context of Culture. Berkley: University of California Press.

Licayo, C. 1981 Report of the Mini-Conference on Hispanic Aging. U.S. Government Printing Office. MCR-25.

Longino, C. 1983 A Statistical Profile of Older Floridians. Center for Social Research in Aging, Miami.

McDermott, Walsh 1960 Introducing Modern Medicine in a Navajo Community. Science 131:197-287.

McKinley, J. 1981 Social Network Influences on Morbid Episodes and the Career of Help Seeking. In The Relevance of Social Science for Medicine. L. Eisenberg and A. Klisman, eds. Pp. 77-107. Dordrecht, Holland: D. Reidel.

Mace, N. and P. Rabins 1981 The 36-Hour Day. Baltimore: Johns Hopkins.

Maldonado, D. 1985 The Hispanic Elderly: A Socio Historical Framework for Public Policy. Journal of Applied Gerontology, in press.

Markides, K. 1983 Minority Aging. In Aging in Society Selected Reviews of Recent Research. M.W. Riley, B.B. Hess, and K. Bonds, eds. Hillside, New Jersey: Lawrence Erlbaum Associates, Inc.

Middleton, L. 1984 Alzheimer's Family Support Groups. Suncoast Gerontology Center, University of South Florida Medical Center, Tampa, Florida.

Morgan, M., D. Patrick and J. Charlton 1984 Social Networks and Psychosocial Support Among Disabled People. Social Science and Medicine 19:489-497.

Mortimer, J. and L. Schuman 1981 The Epidemiology of Dementia. New York: Oxford.

New, P.K., J. N. Henderson, and D.K. Padgett 1985 Aging, Ethnicity and the Public: Policy Implications. Journal of Gerontology, in press.

Parsons, T. 1958 Definitions of Health and Illness in Light of American Values and Illness. E.G. Jaco, ed. Pp. 165-187. New York: Free Press.

Paul, Benjamin, Ed. 1955 Health, Culture, and Community: Case Studies of Public Reactions to Health Programs. New York: Russell Sage Foundation.

Pfeiffer, E. 1985 Alzheimer's Disease: A Florida Perspective Hearing before the Select Committee on Aging, House of Representatives, 98th Congress, Second Session, Committee Publications No. 98-476. Washington: U.S. Government Printing Office.

Polgar, Steven 1962 Health and Human Behavior: Areas of Interest Common to the Social and Medical Sciences. Current Anthropology 3:159-205.

Pynoos, J., B. Hade-Kaplan and D. Fleisher 1984 Intrergeneratinoal Neighborhood Networks: A Basis for Aiding the Frail Elderly. The Gerontologist 24:233-237.

Reisberg, B. 1981 Brain Failure. New York: Free Press

Rowe, J. and R. Besdine 1982 Health and Disease in Old Age. Boston: Little, Brown.

Sokolovsky, J. and C. Cohen 1980 Being Old in the Innter City: Support Systems for the SRO Aged. In Dimensions: Aging, Culture and Health. C. Fry, ed. Pp. 163-184. Brooklyn: Bergin.

Walker, N.K., A. MacBride, and M.L.S. Vachon 1977 Social Support Networkds and the Crisis of Bereavement. Social Science and Medicine 11:35-41.